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AUTHOR Mellins, Claude A.; And Others
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ABSTRACT

Caregiving studies often focus on the impaired elder who is the care receiver and the one family member who is perceived as the primary caregiver. Such studies fail to consider all members of the family, whether or not they are involved in providing care. This study was conducted to explore the effects of an elder's health-related dependency on the family network through the eyes of family members other than and including the primary caregiver and care receiver. It focused on the nature of the caregiving experience and the types of changes that family members experience in response to a health-related dependency. Subjects were participants in the University of Southern California's Longitudinal Study of Generations and included 20 families interviewed in 1973, 1985, and 1986. Semi-structured interviews concerned with the health decline of the older family member and the effects on other family members were completed by an average of three to four members per family. The results suggest that: (1) caregiving is often a shared responsibility between either multiple primary caregivers, very involved secondary caregivers, or both; (2) a substantial part of the family network is affected by the experience of caregiving for an older adult; (3) the effects on family relationships are often positive as well as negative; and (4) network effects include altered perspectives about aging, one's own mortality, and other family members. (NB)

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# CAREGIVING AS A FAMILY NETWORK EVENT

Claude A. Mellins, Sandra L. Boyd and Margaret Gatz

Department of Psychology
and
Ethel Percy Andrus Gerontology Center
University of Southern California
Los Angeles, CA 90089-0191

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With the increasing life expectancy and morbidity of the elder population, having to provide care for an impaired older adult has become a major life event experienced by today's families. A vast caregiving literature reflects substantial concern with the effect on the family members of providing such care (Abel, 1987; Horowitz, 1985; Zarit, Orr & Zarit, 1985). Most studies to date have emphasized that caregiving duties fall primarily on one individual in the family, i.e., the spouse of the frail elder, or an adult child, usually a daughter (Horowitz, 1985). These studies have usually examined the direct effects of providing care on the caregiver, especially negative feelings such as isolation and burden. In two exceptions to this pattern, Rosner and Matthews (1985) have suggested that major caregiving responsibilities may be shared among family members more often than current literature suggests, and Moss (1987) has noted positive effects from the caregiving experience.

Focusing on the impaired elder and the one solitary caregiver may obscure some of the complexities of a caregiving situation for families as a whole. Pruchno, Blow and Smyer (1984) argue that major life events have effects that ripple throughout the family, making the family network a key unit of analysis in studies of life changes. From such a perspective, what is often missing from caregiving studies is consideration of all members of a family, whether or not they are involved with providing care.

This paper explores the effects of an elder's health-related dependency on the family network through the eyes of family members other than and including the primary caregiver and care recipient. More specifically, we were interested in the nature of the caregiving experience and the types of changes that family members experience in response to a health-related dependency. First, we hypothesized that caregiving responsibilities would often be shared by multiple family members. Second, we hypothesized that caregiving and the health related dependency of an elderly family member would alter multiple relationships within the family network, e.g., between a caregiver and his or her adult child. Third, we expected families to indicate positive as well as negative effects of caregiving on the family. Finally, we hypothesized that exposure to the health declines of an older family member would result in family members, particularly the adult grandchildren, having a change in life perspective, either in terms of themselves or other family members (Hagestad, 1981).

## METHODS

### Subjects

Subjects were participants in the USC Longitudinal Study of Generations (Richards, et al., in press). For testing the present hypotheses, a subsample of 20 families interviewed in 1986 were selected. These 20 families were part of 369 families

(1331 individuals) surveyed in 1972 and 1985. The oldest generation (G1) had a mean age in 1985 of 78; their children (G2s) had a mean age of 57; and the G3s had a mean age of 33. Families were selected for interview if at least two generations lived within 75 miles of USC, if at least one family member identified him or herself as a caregiver in the survey, and/or if any respondent indicated that the G1 showed signs of a memory disorder. In each family, extensive in-person interviews were sought from the impaired elder, his/her spouse, an adult child, the adult child's spouse, and a young adult grandchild. On the average, we obtained 3 to 4 interviews per family.

It is important to note that these caregiving families were not recruited for a study of caregiving; rather they are participants in an ongoing longitudinal study of families. Thus, the present study may be more representative of families experiencing the decline of an older adult than are typical studies which advertise for caregivers and therefore have essentially a clinical population.

Measures

A semi-structured interview was developed for the purpose of this project and has been described in detail elsewhere (Hurwicz, 1986). Much of the interview concentrated on the health decline of the older family member and the effects on the interviewee and the rest of the family from the interviewee's perspective.

In order to describe these effects, three general categories

were developed for coding responses: altered relationships, altered perspectives and health and psychosocial effects. Each category consisted of four to eight specific codes (Table 1). These codes were developed based on a review of the literature and a preliminary examination of 8 interviews (Gatz, Boyd, and Mellins, 1987).

In addition, the care recipient's level of impairment was assessed in the interview by: 1) asking all family members, including the frail elder when possible, to report on the G1's health problems and ability to handle daily activities, and 2) by administering a mental status questionnaire to the G1 care recipient. Finally, each interviewee was asked in some detail about each family member's contribution to caregiving, including the nature and extent of activities, as well as to complete a Burden Scale (Zarit, Reever, & Bach-Peterson, 1980).

## RESULTS AND DISCUSSION

### SAMPLE CHARACTERISTICS

Level of Impairment of elderly family member. This sample consisted largely of severely impaired older adults who required considerable care. Fifty-five percent of the G1s required full-time assistance and in half of the families, the care recipient was living with a family member. Forty-two percent of the families hired outside help to assist with care. The level of impairment of this sample is also reflected in the mental status

scores of the care recipients. Most of the care recipients (all but two) were not able to answer more than 70% of the questions.

Level of stress on primary caregivers. Overall scores on the burden scale suggest that the primary caregivers in this sample were experiencing significant psychological distress as a result of caregiving. Examination of the interview responses also indicated significant emotional and physical effects of the caregiving experience on the primary caregiver. With only two exceptions, all families made reference to health and psychosocial effects of caregiving on primary and secondary caregivers. Seventy-two percent of these references were to emotional/psychological effects such as mental strain, frustration, anxiety, sadness, resentment, and mental fatigue; fourteen percent were to physical health effects.

TESTS OF HYPOTHESES

**1. Caregiving responsibilities are often be shared by multiple family members.**

While most of the families could identify a primary caregiver when asked to do so, multiple family members indicated that they were substantially involved in providing assistance. Not all families agreed on who the primary caregiver was, but many families did describe caregiving as a team effort. On average, three members of the family were significantly involved in caregiving; often there were four members and paid help outside the family network. One third of these families indicated that

two or more people shared primary responsibilities, and slightly less than half of the families had very involved secondary caregivers. For example, in one family the G2 siblings split the responsibilities--the son was responsible for at-home medical care, while the daughter managed the G1's finances. In another family, a G2 son was "on-call" daily for his mother who was providing extensive personal care for his father. Finally, in several families, a married couple (G2s) shared the responsibility for taking care of one of their parents. The following quote summarizes the prevailing feeling described by these families: "Yeah, they really pitched in and I couldn't have done it without them, you know, it was really kind of a team type thing . . . it's probably the way our family does things. You know, who's available, who's willing."

**2. Caregiving and the health related dependency of the elderly family member will alter multiple relationships within the family network.**

With few exceptions, each family member referred to at least one altered relationship. On an average, each family interviewed mentioned 13 altered relationships between different pairs of family members. The most frequently reported changes in family relationships were: increased/decreased closeness, increased/ decreased tension, increased social support, and changes in the amount of time family members spent together. These results suggest that the effects of caregiving go beyond the primary

caregiver and care recipient and therefore the entire family network is an important unit of analysis.

**3. Families will indicate positive as well as negative altered relationships in the family network.**

In all but two families, positive changes in family relationships were reported, e.g., family members "grew closer", "spent more time together", "and were more supportive of each other" as a result of G1's health related dependency. One third of all references to altered relationships were positive and over one third of the families actually reported more positive changes than negative ones. However, as in previous literature, there were also many references to negative effects of caregiving; 58% of the families reported more negative than positive altered relationships. The most common negative change reported by these families was increased tension or conflict between primary caregivers and the care recipient or between the primary caregiver and other family members who were not as involved. In some cases, the tension was caused by the perception that these other family members were not "doing their fair share." In addition, family members were frequently not able to spend as much time together because of caregiving responsibilities and/or because of increased tension or conflict.

In families who reported considerably more negative relationships than positive ones, the G1 was <u>extremely</u> impaired, and/or there was a history of family conflict. In families where

there were more positive changes, there was a range of impairment in the G1, from minimal to severe.

In conclusion, when multiple family members were asked to report on the effects of caregiving in the family, positive as well as negative effects were expressed.

**4. Exposure to the health declines of an older family member will result in family members having a change in life perspective, either in terms of themselves or other family members.**

Almost all families included at least one interviewee who indicated a changed perspective about family members or their own place in the life cycle, as a result of either the G1's illness or the caregiving experience. Interestingly, over two thirds of all interviewees who described a changed perspective were secondary caregivers, usually G3s or spouses of G2 caregivers who were not as involved with the care recipient. It is possible that this distance gives these family members a more objective perspective about caregiving and aging. However, it should also be pointed out that these secondary caregivers also experienced some psychological stress as a result of watching not only the care recipient's health decline, but their parent's or spouse's reaction to caregiving.

Examples of changed perspectives included recognizing one's own mortality as well as that of one's parents and grandparents, and appreciating previously unrecognized strengths and

vulnerabilities in the parent or spouse. One G3 said, "watching my grandmother makes me face my own aging process and mortality."

## SUMMARY

In conclusion, the results of this study suggest that (1) caregiving is often a shared responsibility between either multiple primary caregivers, very involved secondary caregivers, or both, (2) a substantial part of the family network is affected by the experience of caregiving for an older adult, (3) the effects on family relationships are often positive as well as negative, and (4) network effects include altered perspectives about aging, one's own mortality, and other family members. These results show that considering the family network as the primary unit of analysis can give a more comprehensive view of the caregiving experience.

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**TABLE 1**

**LIFE EVENT WEBS:**
**EFFECTS OF CAREGIVING AND HEALTH RELATED DEPENDENCY**

**ALTERED RELATIONSHIPS***

Closeness
(e.g., mother and daughter grow closer by taking care of grandmother)

Conflict/Tension
(e.g., disagreements between G2 siblings as result of differential caregiving duties)

Social Support
(e.g., G2 caregiver talks about greater social support from spouse since mother became ill)

Change in Time Spent Together
(e.g., family members spend more or less time together since care recipient became ill)

Competing Demands
(e.g., G2 caregiver feels she must balance job responsibilities with caregiving for a parent)

Financial Changes
(e.g., G2 changes will to provide for G1 care recipient)

Protecting Care Recipient
(e.g., family agrees not to discuss stressful situations around care recipient)

Altered Roles
(e.g., G2 daughter perceives herself as "parent" for G1 care recipient)

*Altered relationships were coded for direction (positive or negative) as well as content.